Bereaved Parent Quotes and Potential Quality Measures

Sub-Theme	Quote
Education Needs	
At EOL	I didn't know some things like I know now. And if I would've knew them... I would've did better then… I felt like hospice should've came in when they told me his heart wasn't –... I found out all this kind of stuff after he passed. [86B]
Opportunity to Plan for Location of Death	It just really depends on the parent. If it's possible they could do it at home and the parent would like that, then I would say home. If the parents would want the hospital, then the hospital… I'd probably want to be at peace and I'd be at home just to be away from the noise, be away from the doctor. (162B)
After Death	After she passed away we didn't really know – like they had offered us to do like a bath or this and that…there was a lot of directions so we didn't really wind up doing much, and I kind of wish we would have had more like…I mean just some guidance. [67W]
Goal Concordant EOL Care	
Going down swinging	In my mind, it's a privilege to fight. Not everybody gets a chance to have a child and have them go through an illness or an accident or whatever the case may be and have that opportunity to fight to give them life. [64W]
Comfort based care	I wouldn't want them to suffer…once their time comes…let them go, 'cause there's no point in them continuing to hurt, and trying to bring them back, to continue, again, to hurt. I don't think that's fair…just try your hardest just to make them somewhat comfortable. (152B)
Patient and Family Centered Care	
Sincerity in caring for patients	If I stepped out for a couple of hours of the day, I'd come back and his room was decorated, and he'd have on clothes, and stuffed animals. . . [I]t made me feel like they actually cared about my baby, people actually loved him the same way I loved him. [155B]
Not being alone during difficult decisions	She [the nurse] would always come into the room and she would sit with us. [160B]
Siblings	Our children were pretty young…we had to make some decisions about when to let them come up, if to let them come up. I mean, I guess a little bit of clarification or advice on what to have done with that would have been helpful. [120W]
Parents can be parents and kids can be kids	Well, being a mom, the main thing that we ever want to do is hold our baby. Especially heart babies, they have a lot of tubes and things connected to them. But we knew that it was coming close to the end of her life. So, they would just allow me to hold her. They would allow me to give her baths. They would allow me to dress her as much as I could…So, that was special to me. Just to be able to still be her mom even in the worst-case scenario. [129B]
Financial Support	[T]he social worker that was in the transplant team, she was really awesome. She talked to me about our financial needs, and she got me a list of resources for financial assistance. (33HW)
Bereavement Needs	
Grief Counseling Offered	I just think a lot of support…not just… before but after as well…Our pediatrician gave us some information about a non-profit that provides grief counseling, and that was really, really beneficial… it's all free…you can go as many times as you want…I just think it's important to maintain some kind of follow up with…families after their children have passed away because…it is devastating. (99NHW)
Condolences from team	I guess I would have expected maybe one or two of the doctors that I did get close with to call me and just check on my well-being or even check on the twin. I feel like, 'Goodness, do you all think about the babies after they're gone?' [129B]
Child Legacy	I was afraid people would forget him, because he didn't have a full life to make memories. I think that parents want to feel like their child is remembered and that their child made an impact on this world, no matter if they were here for a day or, you know, a year or 20 years. [99W]

Potential Quality Measures

1. Education Needs

a. *Palliative care involved within 30 days before death (adult and pediatric oncology)*[1, 2]
b. *Anticipatory guidance around what to expect with the child's death (pediatric oncology)*[2]
c. *Hospital policies to make a less restrictive environment at EOL (e.g. eliminating visiting hour restrictions) (pediatric oncology)*[2]
d. *Documented communication regarding prognosis between healthcare team and parents (pediatric oncology)*[1]
e. *Annual training for all team members to cover difficult conversations and considerations for caring for a child at EOL (novel)*
f. *Onboarding training for all team members to cover difficult conversations and considerations for caring for a child at EOL (novel)*

2. Goal Concordant EOL Care

a. *Did they get the help they wanted for pain (American Academy of Hospice and Palliative Medicine [AAHPM])*[3]
b. *Documentation of a goals of care discussion (pediatric oncology)*[1]
c. *End-of-life care aligned with goals (pediatric oncology)*[1]

3. Patient and Family-Centered Care

a. *Did the parents feel their other children (siblings, close children) were heard and understood (AAHPM)*[3]
b. *Documentation of anticipatory guidance around how to support other children (siblings, close children, etc.)? (pediatric oncology)*[2]
c. *Assessment of sibling/other key child needs within 30 days before or after day (pediatric oncology)*[2]
d. *Did the parents feel heard and understood (AAHPM)*[3]
e. *Did the parents feel their child was heard and understood (AAHPM)*[3]
f. *Social risk screening within 30 days before or after death (pediatric oncology)*[2]
g. *Hospital policies around continuity of nursing care at EOL(novel)*
h. *Child life involvement within 30 days before or after death (novel)*

4. Bereavement Needs

a. *Presence of a bereavement program (pediatric oncology)*[2]
b. *Programs maintain a list of bereavement resources (ideally with 1:1 and group options) (novel)*
c. *Families offered a list of bereavement resources within 30 days of death (novel)*
d. *Memory making or legacy making was done with the child and family (novel)*

1. Ananth P, Mun S, Reffat N, et al: Refining Patient-Centered Measures of End-of-Life Care Quality for Children With Cancer. JCO Oncol Pract 18:e372–e382, 2022

2. Johnston EE, Martinez I, Wolfe J, et al: Quality measures for end-of-life care for children with cancer: A modified Delphi approach. Cancer 127:2571–2578, 2021

3. Quality Measures Project - National Coalition For Hospice and Palliative Care [Internet][cited 2023 Nov 21] Available from: https://www.nationalcoalitionhpc.org/qualitymeasures/

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